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Objective: The research sought to evaluate whether providing personalized information services by libraries can improve satisfaction with information services for specific types of patients.

Methods: Adult breast cancer (BrCa) clinic patients and mothers of inpatient neonatal intensive care unit (NICU) patients were randomized to receive routine information services (control) or an IRx intervention.

Results: The BrCa trial randomized 211 patients and the NICU trial, 88 mothers. The BrCa trial showed no statistically significant differences in satisfaction ratings between the treatment and control groups. The IRx

group in the NICU trial reported higher satisfaction than the control group regarding information received about diagnosis, treatments, respiratory tradeoffs, and medication tradeoffs. BrCa patients posed questions to librarians more frequently than did NICU mothers, and a higher percentage reported using the website. Questions asked of the librarians by BrCa patients were predominantly clinical and focused on the areas of treatment and side effects.

Conclusions: Study results provide some evidence to support further efforts to both implement information prescription projects in selected settings and to conduct additional research on the costs and benefits of services.

INTRODUCTION

Patients' needs for quality health-related information is a consistent focus of the Institute of Medicine's "Crossing the Quality Chasm" report [1], with its ten general principles that include calls for patients' unfettered access to clinical knowledge, for information enabling informed decisions about treatment choices, and for the information and opportunity for patients to exercise control over their care. Similarly, the 2008 to 2012 Coordinated Federal Health Information Technology (HIT) Strategic Plan for the Office of the National Coordinator for HIT has made "personalized health" key to its strategy for improving the quality and efficiency of health care through the HIT infrastructure [2]. Much patient information today comes via the extensive resources available on the Internet [3], underscoring questions of what material is best suited to a particular patient situation [4] and how patients will find the most appropriate resources [5].

The term, "information prescription" (IRx), has been used in the literature to refer to a number of efforts designed to provide specific, evidence-based information to patients. Although the term has been used to include bibliotherapy [6], most of these instances have involved the physician or provider

This article has been approved for the Medical Library Association's Independent Reading Program http://www.mlanet.org/education/irp/.

Supplemental Appendix A, Appendix B, Appendix C, Table 2, and Table 3 are available with the online version of this journal.

Highlights

- The information prescription (IRx) services as implemented at Johns Hopkins were customized to the
 particular patient group served and involved both web
 resources and access to a librarian. This evaluation
 was the first controlled clinical trial of a library-based
 IRx service.
- Outcomes of the prescription service were somewhat different for the adult breast cancer (BrCa) clinic patients and mothers of inpatient neonatal intensive care unit (NICU) patients. BrCa patients and NICU parents receiving information prescription services reported greater satisfaction with the overall information they received, but BrCa patients did not experience significantly greater satisfaction.
- Both NICU parents and BrCa patients used the website and librarian services. Levels of use were greater for the BrCa patients. BrCa patients in the treatment group also expressed greater levels of reassurance with the information they received from Hopkins.

Implications

- Implementation of IRx services requires close collaboration with health care providers in terms of both content and logistics.
- Libraries considering implementing IRx services would be wise to begin with one patient group and to carefully consider what group might benefit most from such services.
- Study results provide a basis for further testing of IRx services and related information use concepts.

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making referrals to websites containing evidencebased literature or protocols [7–12]. The idea has also been extended to the automated development of information for patients [13] and a means of conveying guideline information [14].

A growing number of IRx projects have involved libraries. Assisting individuals in finding information is a traditional library function, and libraries have long provided services to people in search of health information through a variety of mechanisms. The National Library of Medicine (NLM) has supported, particularly through the National Network of Libraries of Medicine (NN/LM) http://www.nnlm.gov, the development of consumer health services in public libraries and cooperative consumer health efforts involving public and academic medical libraries. Some hospitals and other health care operations include patient libraries, and some academic medical center libraries provide services to patients as well as to faculty and students.

An early library-initiated patient information service involved developing customized searches for patients [15]. In 2002 to 2005, the American College of Physicians and NLM conducted a program of IRxs involving referral to relevant portions of MedlinePlus [16]. Virginia Commonwealth University librarians conducted focus groups to identify physician-perceived barriers to filling IRxs [17]. Librarians at the University of Missouri developed selected links to MedlinePlus for patients [18], and University of Vermont librarians worked collaboratively with a family medicine practice to integrate an IRx service [19]. The study reported on here was also developed collaboratively with clinicians. It made use of a locally developed website and included access to a librarian as a part of the intervention.

This study sought to answer the following questions:

- 1. What impact would a library-based, proactive information service have on patients' general satisfaction with information services?
- 2. How would these information services be used?
- 3. How might different clinical contexts affect these answers?
- 4. Are providers' perceptions of the need for an information service a good predictor of that need?

By addressing and answering these four questions, the study team hoped to provide other institutions with information that they could use in considering an IRx service for their own environment. These questions were translated to the primary hypothesis, "overall satisfaction of participants who received proactive information services would be greater than that of participants receiving standard information services."

Conversations with the Johns Hopkins adult outpatient breast cancer (BrCa) clinic led to the initial selection of that setting. Anticipating that the patients' disease, its severity, and the clinical setting would be important factors, the Johns Hopkins Neonatal Intensive Care Unit (NICU) was subsequently selected to provide a strong contrast in terms of both patients and setting.

In the case of providers, the researchers were concerned that the information service would be perceived as interfering with the patients' care and interested in whether their perception of the service would change during the course of the study as a result of having experienced the service.

METHODS

Study populations and clinical settings

Study sites included two Johns Hopkins BrCa outpatient sites (the outpatient center, on Johns Hopkins' main medical campus, and Greenspring Station, a suburban outpatient clinic) and two NICU sites (the Johns Hopkins Hospital [JHH] and Johns Hopkins Bayview Medical Center [JHBMC]).

Typically, the BrCA program (6 physicians and 2 breast-cancer-dedicated nurse practitioners) sees about 600 new patients each year. In general, 80%–85% seek primary treatment opinions, and 15%–20% seek a second opinion. All first-visit BrCa patients seen at either clinic site were eligible for this study.

The JHH neonatal unit is a level IIIC NICU with 45 beds and treats over 700 babies per year. The JHBMC NICU, designated level IIIB, houses 25 beds and treats over 400 babies a year. Admissions to the NICUs are more representative of the immediate neighborhoods than the BrCa clinics, despite high-risk infant transfers from across the state and beyond. All English-speaking biological mothers (or consenting guardians) of premature infants less than 37 weeks gestational age born at or transferred to the JHH or JHBMC NICUs were eligible. Mothers of infants at greater than 80% risk of mortality based on the score for neonatal acute physiology (SNAP-II) [20] were excluded.

While both study populations might have included males, in fact, all study participants completing the study were women.

Study design

Unmasked randomized controlled trials were performed in each of the two clinical environments, the adult outpatient BrCa setting and the inpatient NICU setting. In each, all participants received standard clinical care, including routine information provision from clinical health care providers. Patients from the BrCa outpatient services and mothers of infants in the NICU in the intervention groups were also offered additional information services, including access to a tailored website and the availability of a librarian.

Previous studies have indicated that patients' educational and reading levels, experience with information technology, experience with and severity of their medical conditions, and place in the disease-management sequences all influence their health information-seeking behavior [4, 21]. Sampling was thus stratified on the basis of access to the Internet and, for BrCa patients, prior experience with breast cancer and extent of disease.

Target sample sizes were set based on the standardizing data from a 10-hospital validating study of

the Patient Judgment of Hospital Quality (PJHQ) instrument [22]. With the goal of detecting a difference in the mean patient satisfaction score of 0.30 units (=1/3 standard deviation) at a significance level of 0.05, the researchers set the sample sizes at 150 patients in each arm of the BRCa setting and 88 mothers in the NICU setting. An interim analysis of the results for the BRCa patients, performed 9 months into the study period, showed a positive but not significant difference between the intervention (IRx) and control groups. A prospective sample size calculation using conditional power analysis suggested 4,400 more patients would be needed to recruit the desired number of participants. As a result, the study was stopped at that point with an enrollment of 211. For the NICU setting, the goal was achieved at 88 patients, and enrollment ceased at that point.

In the BrCa clinic, eligible patients were identified from registration and appointment records in advance and were sent information about the study, including a consent form. When they arrived at the clinic, a study staff member approached them, and if the patient agreed to participate, obtained consent and collected baseline data including prior experience with breast cancer, Internet access, and severity of breast cancer (based on disease stage). Patients were randomly assigned to the treatment or control group, based on these characteristics. Following their consultation, the study staff gave members of the intervention group an information packet. Study librarians contacted patients in the intervention group by telephone or email at one-week intervals for two weeks post-enrollment to offer assistance with any information needs the patient might have. Clinical questions posed by participants were triaged to the provider by inserting a summary as a "patient information prescription note" in the electronic patient record and emailing the summary to the patient's provider. At four weeks or as soon as the enrollee could be reached by telephone by study staff, the exit survey was administered. When an enrollee could not be reached by telephone, a paper survey was mailed with a stamped, pre-addressed return envelope.

The NICU workflow was similar, except that the study nurse sought participation and mothers were randomized only according to Internet access. The study librarian on duty would come to the NICU, when possible, to meet the mothers. When a face-to-face interaction was not possible, a protocol similar to that for the BrCa study was followed: The librarians called or emailed the mothers, offering assistance each week postenrollment for two weeks, up to three times a week.

The study design took into consideration the emotional impact of a diagnosis of cancer and the birth of a premature infant on study participants. The literature suggests that because of the emotional impact of the diagnosis, patients and parents of children vary in the timing and extent of their information needs [23–25]. Therefore, participants were given several weeks to take advantage of the information services. The patients also chose when to seek information and determined how much information

they received. Information services were tailored to their needs. Study librarians were experienced and trained in providing information to patients.

The study was approved by the Johns Hopkins Institutional Review Board. The BrCa intervention lasted from September 2005 through October 2006, and the NICU intervention from December 2006 to April 2008.

Study librarians and participant study flow

The seven librarians who provided services as part of the study had completed training in consumer health information and met the requirements for Consumer Health Information Specialization as specified by the Medical Library Association [26]. One librarian was also a registered nurse. Librarians took the role either of study staff or study librarian for a given patient, to keep administrative and information-provision functions separate.

In both settings, the project team worked closely with the research and clinical staffs to define the work flows and logistics for the clinic. The investigative team presented the study to the clinic providers to elicit feedback and to establish buy-in to the project. Pilot studies were conducted to adjust the logistics and to improve the clarity of the survey wording and assessment tools.

Intervention

Librarians built a collection of existing and new condition-specific information and a list of authoritative information sources on a website for each group, which was then vetted by the clinical providers and used as a starting resource for providing patient information services (Figure 1, online only). When patients or mothers were contacted by a study librarian, the librarian conducted a reference interview, explained how to access the website, and offered assistance in locating information relevant to the needs of the patient.

Information on demographics and potential covariates obtained at baseline included age, race, highest level of education achieved, marital status, work outside the home, level of work, reading ability, and current level of functioning. Reading ability was measured by the Rapid Estimate of Adult Literacy in Medicine (REALM) instrument [27], which has a maximum reading-grade level of eight, and current level of functioning (physical and mental) was assessed by the SF-12 [28].

An exit survey (Appendix A, online only) and records of service usage were used to evaluate the effectiveness of the intervention. The survey questions were based on a prior survey used at Johns Hopkins [29] and assessed overall satisfaction with the provided information by addressing satisfaction with information related to specific components of care (radiation therapy, chemotherapy, etc.) and information from different sources within Johns Hopkins (doctors, nurses, website, etc.) and outside of Johns

Hopkins. The survey scale ranged from 1 ("Poor") to 5 ("Excellent"). Additional questions were added to the exit survey to assess the impact of the information obtained on the respondents' feelings and on treatment decisions and behavior. The exit survey also provided information on use of the website.

The overall study design included surveys of providers before and after the study to gauge their perceptions of patient response.†

RESULTS‡

Patient demographics

In the BrCa intervention, 211 (45%) of 473 eligible patients were randomized (105 IRx, 106 control); 185 (88%) of those randomized completed an exit survey. In the NICU intervention, 88 (33%) of the 267 mothers approached were randomized (44 IRx, 44 control). A total of 59 (67%) mothers completed the exit survey.

There were statistically significant differences between participants in the two settings (Table 1). Further details are available in Table 2 (online only). BrCa subjects (whether they received an IRx or were a control) were predominantly Caucasian and older, worked more out of the home, had more experience with their disease, had higher reading levels, and had greater Internet access. There were no statistically significant demographic or satisfaction differences between the intervention and control groups in either the NICU or BrCa setting.

Satisfaction

Results for the overall and individual component of care satisfaction scores are shown in Figures 2, 3, 4, and 5.

Among the BrCa participants at exit, there were no statistically significantly differences in satisfaction ratings between the 2 arms for any single component of care. Mean overall satisfaction was 3.06 in the IRx group and 3.04 in the control group. In the NICU population at follow up, the intervention group rated several specific areas significantly higher than the controls (diagnosis (3.7 vs. 3.1, t(86)=2.49, P=0.015); treatments (3.6 vs. 2.9, t(86)=2.56, P=0.012); respiratory tradeoffs (3.4 vs. 2.6, t(86)=2.9, P=0.005); and medication tradeoffs (3.4 vs. 2.8, t(86)=2.46, P=0.016)), and they rated overall satisfaction higher as well (3.6 vs. 3.1, t(86)=1.87, P=0.065), although not statistically significantly higher. A comparison of mean satisfaction scores in the BrCa and NICU studies, after correcting through regression for particular satisfaction types with an unpaired t-test, showed that the NICU mothers reported a statistically significantly higher mean overall satisfaction (3.1) than did the BrCa patients (2.7, t(112), P<0.001) (Table 3, online only). Overall satisfaction scores for patients or parents making use of the

intervention, that is, using the website or asking a question of the librarian, were compared with scores for participants in the intervention group who did not use the service, alone or pooled with the control group, and no significant differences were found in either case.

With regard to specific sources of information, the NICU intervention group mothers rated a number of sources differently than the control group mothers (Figure 5): the quality of information received from doctors and nurse practitioners (mean score of 3.5 vs. 3.0, t(87) = 2.14, P = 0.041); nurses (3.6 vs. 3.1, t(87) = 2.23, P = 0.032); and other sources of information (3.5 vs. 2.8, t(87) = 2.66, P = 0.012). A regression model that pooled resources "inside" Johns Hopkins separately from resources "outside" indicated that the NICU mothers rated Hopkins resources higher than "outside" resources by a difference of 0.16 (P = 0.004) rating points. The NICU IRx mothers, however, rated "inside" resources even higher, as seen in an interaction effect with an additional beta-coefficient of 0.16 (P = 0.008) separate from the overall "inside" effect.

Further analysis of the survey data uncovered some interesting results regarding 2 variables potentially related to satisfaction: impact on decision making and reassurance. In the BrCa setting, in an open-ended question about whether the information obtained at Johns Hopkins changed their decisions about treatment or care, 44 (48%) of the control patients stated that received information changed their decisions, whereas only 28 (33%) in the IRx arm made an equivalent statement (P=0.025). The latter group however, included many patients who said that the information made them feel better. This finding was supported by responses to the question, "Did the information you receive reassure you?" Forty (47% of 85 reporting participants) of the IRx group patients said the information provided by Johns Hopkins reassured them, and 33 (36% of 92 reporting participants) of the control patients also said so (P=0.045).

In contrast, 28 (88% of 32 reporting mothers) of the IRx group mothers reported that received information reassured them, but so did 24 (92% of 26 reporting mothers) of the control group mothers. Only 4 mothers reported that information received during their infants' stays at Johns Hopkins was associated with changes in decisions, and these were evenly split between the IRx and control groups. The common sentiment was expressed by one mother: "not really, no decisions to be made." However, when asked about the effect of information on surgery in particular, significantly more IRx group mothers (48%) than control group mothers (17%, P=0.04) reported that their experience affected their decisions ("PDA ligation became less scary with more information").

Patients' responses to the surveys also provided qualitative information on both the emotional challenges and the importance of finding out about their conditions, as well as the role that providers played in informing the patients. The stress of these concerns was communicated by one patient: "Sometimes I feel like I'm loosing [sic] my mind, as calm as I may seem." A typical response of an information user was:

[†] The provider survey is further described in Appendix B, online only.

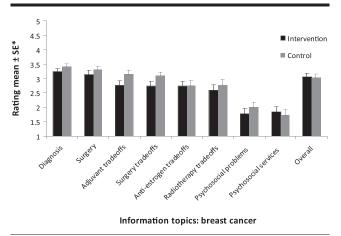
[‡] Additional statistical information is available in Appendix C, online only.

Table 1Participant demographics

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	Works outside home Yes No	55 47	(54%) (46%)	56 45	(55%) (45%)	0.83		1 1	(47%) (52%)	8 50	0.17 (29%) (71%)	0.024	

Where totals do not sum to the sample size, data were not available. * P-value within setting. † P-value between settings.

Figure 2
Exit satisfaction ratings: breast cancer (BrCa) (n=185)



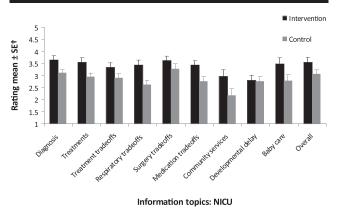
^{*} Scale: 1=Poor, 5=Excellent.

"Thank you. I will look over some of the info at the website but I looked over a lot of this info on my own when I was diagnosed. I will probably be looking at info on radiation eventually." Those who did not use the services were likely to express the sentiments of one of the patients, who said she "has already been given so much information about her diagnosis and treatment that I have no questions at this time. I have received information from other libraries."

Services used

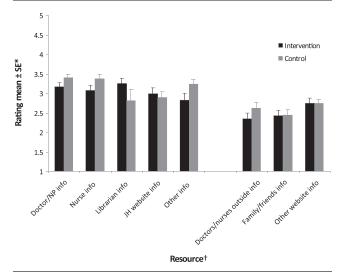
Of the 105 patients in the IRx group in the BrCa study, 26 (25%) had a question managed by the librarian. In the NICU study, 5 of the 44 (11%) mothers randomized to the IRx group received explicit service from the librarians. The higher rate of question asking in the BrCa study was not statistically significantly different (*z* test for proportions=1.6, *P* NS).

Figure 3
Exit satisfaction ratings: neonatal intensive care unit (NICU) (n=59)*



^{*} The following pairs showed statistically significant differences: Diagnosis (P=0.015), Treatments (P=0.012), Respiratory tradeoffs (P=0.005), Medication tradeoffs (P=0.016).

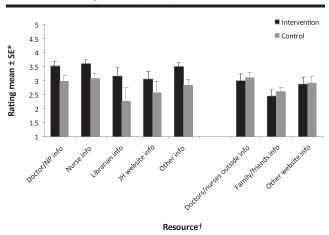
Figure 4
Exit resource ratings: BrCa (n=185)



^{*} Scale: 1=Poor, 5=Excellent.

In the BrCa exit survey, 39 (44%) of the IRx group patients completing the survey reported using the study website, but so did 10 (11%) of the control group patients (*z* test for proportions=4.6, *P*<0.0001). The mean frequency of website use was 3.3 times with a range of 1 to 15 times over the time between enrollment and the survey (on average, 4 weeks). When asked whether the website was consulted, one BrCa patient responded, "My daughter did, every day for the last month." The amount of time spent ranged from 1 minute to 6 hours.

Figure 5 Exit resource ratings: NICU (n=59)



^{*} Scale: 1=Poor, 5=Excellent.

[†] Scale: 1=Poor, 5=Excellent.

[†] Items are sequenced by their order in each survey. The space indicates a separation between resources available at Johns Hopkins ("inside") and resources available elsewhere ("outside").

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Table 4Types of questions posed by study participants to librarians

Question category	Question type	Breast cancer (n)	NICU (n)
Domain (ordered from cause to prognosis)	Etiology/risk factor	1	2
(Genetic testing	2	
	Prevention	1	1
	Anatomy		1
	Diagnosis	4	
	Treatment	31	2
	Side effects	17	1
	Breast reconstruction	3	
	Home care		2
	Prognosis	8	3
Subtotal	_	59	
Information sources (ordered by proximity	Provider communication	1	1
to patient: nearest to furthest)	Access to family members' medical records	1	
	Insurance	3	
	Local support group	1	
	Domain information resources	3	1
	Request for primary literature	2	
	Request for full-text articles	3	
Subtotal		76	
Total		81	14

In the NICU study, 8 of 26 (31%) mothers in the intervention group, but only 1 of 32 (3%) control group mothers, stated that they used the study website. This difference was statistically significant (z test for proportions=2.53, P=0.012).

In both groups, the number of contacts with physicians and nurses and the amount of time spent in those contacts did not differ significantly between the arms.

Information prescription questions

In the BrCa study, 81 questions were posed to librarians by 26 of the 105 (25%) people in the intervention group. In the NICU study, 12 questions were posed to librarians by 5 of the 44 (11%) intervention mothers. In terms of people asking questions, this difference was not statistically significant (*z* test for proportions=1.6, *P* NS).

The types of questions asked of the librarians are shown in Table 4. The content of the questions fell into 14 categories that were then combined, in turn, into questions related to breast cancer and its treatment and questions related to information sources. The treatment-related category accounted for the most questions (48), including side effects (17) and general questions. Sample questions from this group included: "How do specific chemotherapy regimens work and the associated potential pros and cons?"; "What are the issues surrounding the use of ports for receiving chemotherapy?"; and "What foods boost the immune system?" Side-effects questions tended to be specific: for example, adverse effects of Taxol, especially in weekly therapy versus once every 3 weeks.

Questions in the information sources category ranged on a continuum, from information sources that were close and specific to the patient to sources that were far removed and potentially unrelated. The single provider-communication question reflected the patient's lack of clarity in terms of how and when to follow up with the doctor for the next phase of treatment once her radiation treatments ended. The request for information from family members' medical records was related to etiology and genetics, in that the patient wanted to find out if her mother's hysterectomy was caused by the same cancer type as her sister's brain tumor. Another question, on local breast cancer support groups, involved information that clinical health care team members either provide or likely think of as something they provide. Insurance-related questions (3) were another small but important category because requests were related to potential financial barriers to treatment: for example, a patient was unable to get answers about coverage for a test from her insurance company or from the US Health Services Administration.

The three final categories of questions were cancer information resource questions or issues (3), requests for primary literature (2), and full-text requests (3). In the cancer information resource questions or issues category, the librarian was not so much a clinician-extender but acted as the first-line expert to contact. For example, one patient wanted to know the librarian's opinion about a specific book named as a resource.

Requests for primary literature (2) included case studies on patients with the same diagnosis and requests for studies on trastuzumab and HER2-positive early-stage breast cancer. In the three full-text requests, patients either submitted lists of citations they had already gathered for which they wanted the full-text articles, or they specifically asked the librarian for articles on their topics rather than answers to their questions.

In the NICU intervention, most of the 12 specific questions posed to librarians by 5 of the 44 (11%) mothers fit into the categories created for the BrCa patients. The exceptions were 2 home care questions, one having to do with government services for infants with special needs, one having to do with devices to hold premature infants, and one anatomy question

that had no correlate in the BrCa study: "What is patent ductus arteriosus?" While the numbers are small, it appeared that there was less focus on the treatment decision than in the BrCa study.

LIMITATIONS OF THE STUDY

Limitations of the study included the restriction to two patient units and some differences in protocol resulting from logistical aspects of the two studies. Ideally, patients would have been enrolled at the time of diagnosis independent of where they were in the care continuum. For logistical reasons, breast cancer patients were seen in medical oncology clinics. The medical oncology consultation often, but not always, comes after surgery. Much of the initial impetus to seek information and the need for information in these circumstances might have been satisfied during and surrounding the initial surgical consultation for the diagnosis. In addition, there were more potential confounding variables that could have been measured, in particular participants' prior experience with information resources.

DISCUSSION

The findings from this study provide limited support for the primary hypothesis that the overall satisfaction of participants who received proactive services would be greater than that of participants receiving standard information services. There were modest increases in satisfaction, as well as modest use of the services. Some of the results suggest further exploration into information prescription services of this sort and the patient response to them.

The satisfaction data from this study suggest that NICU mothers were more satisfied than the BrCa patients were with the totality of information they received during their hospital experience, whether expressed in terms of clinical problems (diagnosis, treatment) or in terms of the sources of information (doctors, nurses). There were suggestive differences in the two studies regarding satisfaction: In the BrCa study, there were no differences in satisfaction between different components of care; in the NICU study, diagnosis, treatments, respiratory treatment, and medications showed differences in satisfaction among the intervention and control groups.

BrCa patients in the IRx group experienced greater reassurance from received information than did those in the control group. They accessed the librarians and the study website at a rate comparable to that of NICU IRx group mothers. IRx services did not increase or decrease personal access to clinicians.

The observed differences were not thought to be due to differences in the information services received by the two study populations, because the provided services were essentially the same, or to differences in the quality and amount of information provided by the two clinical teams, because participants rated both clinical teams highly. Also, the observed differences were not likely due to differences in overall satisfac-

tion with Johns Hopkins, because the participants showed an ability to differentiate the quality of provided information according to question category.

The observed differences between the BrCa and NICU studies are most likely a reflection of differences in the makeup of the cohorts in the 2 studies. The majority of the BrCa cohort members were Caucasian, and the NICU cohort were African American. The average age of the BrCa cohort was greater than 50 years, while the NICU cohort members were women of childbearing age. BrCa patients had greater Internet access at home, although fully half of the NICU mothers had home Internet access. A majority of the BrCa patients worked outside the home, whereas a minority of the NICU mothers did so. A majority of BrCa patients had dealt with their disease before, although over 90% had "early" disease, while over 80% of the NICU patients had not previously experienced having a premature baby in a NICU. Thus, there are both socioeconomic and disease-related differences between the 2 groups. The relative impact of these factors on satisfaction with IRx services would benefit from further elucidation.

The parent or patient response to the IRx might also be related to information factors such as the amount of information already known, perceived relevance of new information, and receptivity to obtaining more information. Clinicians speak of patient's emotional readiness, and librarians speak of the "teachable moment." These factors varied significantly in the BrCa and NICU settings of this study. Hopkins BrCa patients often entered the study for a second opinion, with prior experience, or otherwise at a late stage in their treatment timeline. In these cases, information needs might have been satisfied to some extent prior to arrival at the clinic. By contrast, NICU parents generally had little or no prior indication of problems that might arise with prematurity.

Patients in the BrCa IRx group used both the website and the librarians more frequently than did their counterparts in the NICU study. Although few data are available on the proportion of users who take advantage of particular library services, it is generally acknowledged that utilization rates of specialized services can be as low as 5% [30]. Thus, it seems that the rate of utilization of the IRx was reasonable.

While the NICU IRx mothers posed questions to the librarians less frequently than did the BrCa patients. NICU mothers were satisfied with more individual sources of information. NICU IRx mothers were also more satisfied with health information from various providers (e.g., doctor, nurse) than were the NICU control group mothers. A possible explanation for the difference in satisfaction without accompanying use of information resources is Wilson's theory of information reserves [31], in other words, that the mere existence of sources that are trusted provide satisfaction to an individual whether they are used in a particular instance or not. Practicing librarians acknowledge this phenomenon, but it is not well documented [32].

At the same time, BrCa patients in the IRx group reported feeling greater reassurance than did their

control counterparts, suggesting that the IRx might affect more than just satisfaction. Assessing the role and relative importance that reassurance plays in patient responses to information would be important for future IRx studies to address.

The decision to implement IRx services at a particular institution requires not only an assessment of effectiveness and provider burdens, as provided in the current study, but also an assessment of costs. While librarians' time spent providing IRx services in this study was documented, the artificial study conditions (particularly the overlap between enrolling subjects and informing them of the service) made it difficult to determine the true costs of providing IRx services.

CONCLUSIONS

This study provides evidence that, in an academic hospital setting, an IRx service can serve as a useful adjunct to existing services to select groups of patients. Given the mixed nature of the results, however, librarians interested in implementing an IRx service at their hospital need to carefully consider what the service would entail, who would be receiving the service, and how it would be integrated into the clinical flow. Consideration should be given to the demographics of potential patient groups as well as to issues of disease severity and the timing of the service relative to diagnosis and treatment stages. A good understanding of the current modes of information provision to patients seems essential to developing supplemental services. Finally, the experience in this study of developing these services suggests the importance of close coordination and collaboration with clinical staff.

The study results also suggest potential areas for further exploration. While there have been other studies about the effect of information prescriptions to Internet information sources, this was the first to explicitly include the services of librarians in the information prescription. Given the study design, it is not possible to separate out the effect of the website from that of the librarian. Given the significant preparation and labor involved in the librarian services, it would be useful to be able to assess the outcomes related to them separately.

This study used overall satisfaction with information services as the primary outcome measure, but also looked at what levels of use were, at whether the patient was reassured by the service or the information provided, and, to a limited degree, at whether the information provided was used in decision making. All of these outcome measures have been used in other studies of information use. More application of them to information prescription studies could enrich understanding of such services as well as contribute to a better understanding of the relationships among the measures.

Finally, the cost of information prescriptions is an issue relevant both to libraries considering such services and to understanding of the relative costs and benefits of library-initiated services. While the

authors were unable to generate useful data on such costs, doing so remains an important consideration.

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REFERENCES

- 1. Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington, DC: National Academies Press; 2001.
- 2. Department of Health and Human Services. The ONC coordinated federal health information technology strategic plan 2008–2013 [Internet]. Washington, DC: The Department; 2008 [cited 4 Apr 2011]. http://www.healthit.hhs.gov/portal/server.pt?open=18&objID=848083&parentname=CommunityPage&parentid=3&mode=2&in_hi_userid=10741&cached=true.
- 3. Fox S. Online health search 2006 [Internet]. Washington, DC: Pew Internet/California HealthCare Foundation; 2006 [cited 4 Apr 2011]. http://www.pewinternet.org/Reports/2006/Online-Health-Search-2006.aspx>.
- 4. Nikoletti S, Kristjanson LJ, Tataryn D, McPhee I, Burt L. Information needs and coping styles of primary family caregivers of women following breast cancer surgery. Oncol Nurs Forum. 2003 Nov–Dec;30(6):987–96.
- 5. Case D. Looking for information: a survey of research on information seeking, needs behaviour. London, UK: Academic Press; 2002.
- 6. Chamberlain D, Heaps D, Robert I. Bibliotherapy and information prescriptions: a summary of the published evidence-base and recommendations from past and ongoing Books on Prescription projects. J Psychiatr Ment Health Nurs. 2008 Jan;15(1):24–36.
- 7. D'Alessandro DM, Kreiter CD, Kinzer SL, Peterson MW. A randomized controlled trial of an information prescription for pediatric patient education on the Internet. Arch Pediatr Adolesc Med. 2004 Sep;158(9):857–62.
- 8. Ritterband LM, Borowitz S, Cox DJ, Kovatchev B, Walker LS, Lucas V, Sutphen J. Using the Internet to provide information prescriptions. Pediatrics. 2005 Nov; 116(5):e643–7.
- 9. Ritterband LM, Ardalan K, Thorndike FP, Magee JC, Saylor DK, Cox DJ, Sutphen JL, Borowitz SM. Real world use of an Internet intervention for pediatric encopresis. J Med Internet Res. 2008 Jun 30;10(2):e16.
- 10. Hand A, Greenwell K, Corbett S, Walker R, Kirrane H. Developing an information prescription service. Nurs Times. 2008 Sep 30–Oct 6;104(39):34–7.
- 11. Houston TK, Sadasivam RS, Ford DE, Richman J, Ray MN, Allison JJ. The QUIT-PRIMO provider-patient Internet-delivered smoking cessation referral intervention: a

cluster-randomized comparative effectiveness trial: study protocol. Implement Sci. 2010 Nov 17;5:87.

- 12. Beaudoin DE, Longo N, Logan RA, Jones JP, Mitchell JA. Using information prescriptions to refer patients with metabolic conditions to the Genetics Home Reference website. J Med Libr Assoc. 2011 Jan;99(1):70–6. DOI: 10.3163/1536-5050.99.1.012.
- 13. Goldberg HS, Morales A. Improving information prescription to parents of premature infants through an OWL-based knowledge mediator. Stud Health Technol Inform. 2004;107(pt 1):361–5.
- 14. Gerlach FM, Beyer M, Berndt M, Szecsenyi J, Abholz HH, Fischer GC. [The DEGAM-concept—development, dissemination, implementation and evaluation of guidelines for general practice]. Z Arztl Fortbild Qualitatssich. 1999 Mar;93(2):111–20. German.
- 15. Williams MD, Gish KW, Giuse NB, Sathe NA, Carrell DL. The Patient Informatics Consult Service (PICS): an approach for a patient-centered service. Bull Med Libr Assoc. 2001 Apr;89(2):185–93.
- 16. Siegel ER, Logan RA, Harnsberger RL, Cravedi K, Krause JA, Lyon B, Hajarian K, Uhl J, Ruffin A, Lindberg DAB. Information Rx: evaluation of a new informatics tool for physicians, patients, and libraries. Inf Serv Use. 2006;26(1):1–10.
- 17. Leisey MR, Shipman JP. Information prescriptions: a barrier to fulfillment. J Med Libr Assoc. 2007 Oct;95(4): 435–8. DOI: 10.3163/1536-5050.95.4.435.
- 18. Coberly E, Boren SA, Davis JW, McConnell AL, Chitima-Matsiga R, Ge B, Logan RA, Steinmann WC, Hodge RH. Linking clinic patients to Internet-based, condition-specific information prescriptions. J Med Libr Assoc. 2010 Apr;98(2): 160–4. DOI: 10.3163/1536-5050.98.2.009.
- 19. Burke M, Carey P, Haines L, Lampson AP, Pond F. Implementing the information prescription protocol in a family medicine practice: a case study. J Med Libr Assoc. 2010 Jul;98(3):228–34. DOI: 10.3163/1536-5050.98.3.011.
- 20. Richardson DK, Corcoran JD, Escobar GJ, Lee SK. SNAP-II and SNAPPE-II: simplified newborn illness severity and mortality risk scores. J Pediatr. 2001 Jan;138(1):92–100.
- 21. Cotten SR, Gupta SS. Characteristics of online and offline health information seekers and factors that discriminate between them. Soc Sci Med. 2004 Nov;59(9):1795–806. 22. Nelson EC, Ware JE Jr., Batalden P. Patient judgments of hospital quality. pilot study methods. design of study. Med Care. 1990 Sep;28(9 suppl):S15–7.
- 23. Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, Bilodeau B, Watson P, Mueller B. Information needs and decisional preferences in women with breast cancer. JAMA. 1997 May 14;277(18):1485–92.
- 24. Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs. 1996 Feb;19(1): 8–19.
- 25. Derdiarian AK. Informational needs of recently diagnosed cancer patients. Nurs Res. 1986 Sep–Oct;35(5):276–81. 26. Medical Library Association. Consumer health information specialization program [Internet]. Chicago, IL: The Association; 2008 [cited 28 Apr 2009] http://www.mlanet.org/education/chc/.
- 27. Davis TC, Long SW, Jackson RH, Mayeaux EJ, George RB, Murphy PW, Crouch MA. Rapid estimate of adult literacy in medicine: a shortened screening instrument. Fam Med. 1993 Jun;25(6):391–5.
- 28. Jenkinson C, Layte R, Jenkinson D, Lawrence K, Petersen S, Paice C, Stradling J. A shorter form health survey: can the SF-12 replicate results from the SF-36 in longitudinal studies? J Public Health Med. 1997 Jun;19(2):179–86.

- 29. Shockney L. The financial benefits of an effective hospitalwide quality assurance/utilization management program. Qual Rev Bull. 1992 Aug;18(8):259–65.
- 30. Personal communications with academic medical library directors and library assessment specialists, Jan 2011. 31. Wilson P. Public knowledge, private ignorance: toward a library and information policy. Westport, CT: Greenwood; 1977.
- 32. Personal communication with Marcia Bates, Apr 09.

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